

**RESEARCH: health information for internal and external research purposes.**

*Recommendations for acceptable and unacceptable data use policies*

**Discussion Question(s)**

1. How important is it for providers to be able to disclose identifiable health care information for research purposes without patient consent?

**Assumptions**

1. Controlling law allows disclosure without consent with specific documentation from researchers (see chart below). However, in practice, most researchers consider these requirements to be burdensome and opt instead to seek patient consent.

**Reccs: Use of Electronically Released Health Information for Research Purposes**

1. Current controlling law (Wisconsin or HIPAA) should set the precedent for:
  - a. Which information can be released electronically for research purposes
  - b. Which entities can receive this information
  - c. Which entities can receive identified (vs. de-identified) information and when.
2. (recommendations to be added following group discussion)

**Current Controlling Law (Wisconsin or HIPAA) – and Suggested Changes**

**Note:** For our 8/21 meeting, please be prepared to point out any areas in the grid below where you would like to recommend a law change as part of the eHealth Action plan.

		Identified Health Information for research purposes		
		Disclose without Consent	Comments: Beyond Required Reporting	Sugg.Change (yes or no)
Type of health information	General health information	Yes <i>W/documentation</i>	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and privacy assurances from the researcher.	
	Mental health	Yes <i>W/documentation</i>	Disclose without patient consent upon documentation of the following - Waiver received from the Institutional Review Board (IRB) or Privacy Board, approval by DHFS and assurances from the researcher relating to patient privacy.	
	Developmental disabilities	Yes <i>W/documentation</i>	Disclose without patient consent upon documentation of the following - Waiver received from the Institutional Review Board (IRB) or Privacy Board, approval by DHFS and assurances from the researcher relating to patient privacy.	
	Alcohol/drug abuse treatment	Yes <i>W/documentation</i>	Disclose without patient consent upon documentation of the following - Waiver received from the Institutional Review Board (IRB) or Privacy Board, approval by DHFS and assurances from the researcher relating to protocols, patient privacy, 3 person independent review and no redisclosure of identifying information (other than to program).	

# RESEARCH DATA USE RECOMMENDATIONS DRAFT – 8/15/06

		Identified Health Information for research purposes (continued)		
		Disclose without Consent	Comments: Beyond Required Reporting	Sugg.Change (yes or no)
	Communicable disease	Yes <i>W/documentation</i>	Disclose without patient consent upon documentation of the following – Waiver received from the Institutional Review Board (IRB) or Privacy Board and affiliation between the researcher and the healthcare provider (affiliation not defined) and privacy assurances from the researcher.	
	HIV test results			
	Genetic testing <sup>1</sup>			
	Sexual assault <sup>2</sup>			
	Domestic violence			
	Adoption			

## Discussion

1. Some members of the group suggested that analyzing de-identified health information to identify evidence-based practices for populations and specific sub-groups could improve patient care.
2. (additional key points to be added following group discussion)

## Considerations

(any suggested policy changes will be placed here following group discussion)

<sup>1</sup> No specific state or federal protection. Federal law pending

<sup>2</sup> May need further research on pre-adoption records.